CLOSING ADDRESS

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INTERNATIONAL CONFERENCE ON RESPIRATORY REHABILITATION AND POST-POLIO AGING PROBLEMS

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CHICAGO, ILL.

(GREETINGS TO HOSTS, GUESTS, ETC.)

I WANT TO THANK THE ORGANIZERS AND SPONSORS OF THIS MEETING FOR INVITING ME TO PARTICIPATE. IT IS TRULY AN HONOR AND A PRIVILEGE TO BE AMONG THIS DISTINGUISHED COMPANY.

DR.GOLDBERG WILL BE HAVING THE LAST WORD TODAY -- AS WELL HE SHOULD -- AND I WANT TO CONGRATULATE HIM AND HIS SEVEN COLLEAGUES ON THE PLANNING COMMITTEE FOR BRINGING TOGETHER IN A COHERENT FASHION A VERY COMPLEX EXPERIENCE IN THE HISTORY OF MEDICINE AND HEALTH CARE.

IN THE FEW MOMENTS I HAVE TO SHARE WITH YOU THIS AFTERNOON, I WANT TO TAKE A LOOK AT WHAT WE HAVE LEARNED FROM THE POLIO EXPERIENCE AND SEE HOW IT CONTRIBUTES TO THE SHAPING OF HEALTH POLICY IN THIS COUNTRY. WE ARE EXTREMELY FORTUNATE TO BE ABLE TO DRAW UPON THE KNOWLEDGE OF SO MANY DEDICATED PEOPLE -- NOT JUST OUR OWN CITIZENS, BUT PEOPLE LIKE ANDRE DESSERTINE, AUDREY KING AND JOSEPH KAUFERT OF CANADA, DR. ADOLPH RATZKA AND HIS COLLEAGUES FROM SWEDEN AND ELSEWHERE IN SCANDINAVIA, AND GEOFFREY SPENCER AND OTHERS WHO HAVE PIONEERED IN THE FIELD OF RESPIRATORY CARE IN GREAT BRITAIN.

WE HAVE EVERY REASON TO BE OPTIMISTIC ABOUT HOW WE CARE FOR DISABLED PERSONS IN THE FUTURE, SINCE WE WILL BE BUILDING UPON SUCH A STRONG FOUNDATION OF KNOWLEDGE, EXPERIENCE, AND COMPASSION.

LET ME SAY, RIGHT AT THE OUTSET, THAT I DON'T WANT TO REPEAT AT THIS TIME A LOT OF INFORMATION YOU HAVE ALREADY RECEIVED IN THE COURSE OF THIS THREE-DAY MEETING. I HAVE HAD A GOOD DEAL OF EXPERIENCE AS A PEDIATRIC SURGEON DEALING WITH MANY FORMS OF RESPIRATORY DISTRESS IN INFANTS. AS MANY PARTICIPANTS HAVE ALREADY NOTED, THE COSTS OF MAINTAINING RESPIRATORY-DEPENDENT INFANTS IN A HOSPITAL SETTING ARE ASTRONOMICAL -- AND THEY ARE NOT LEVELLING OFF.

THESE ARE THINGS YOU KNOW FROM YOUR OWN EXPERIENCES TREATING INFANTS, YOUNG PEOPLE, AND ADULTS, OR AS VICTIMS OF PARALYTIC POLIO. THE ISSUES YOU ARE WRESTLING WITH, HOWEVER, DO NOT EXIST IN A VACUUM, AS YOU WELL KNOW ALSO. HENCE, I BELIEVE MY BEST CONTRIBUTION TO THIS MEETING CAN BE TO HELP ILLUSTRATE WHAT THE FEDERAL GOVERNMENT'S PERCEPTION OF THIS ISSUE MAY BE, HOW IT RELATES TO THE BROADER CHALLENGE OF DEFINING THE FEDERAL ROLE IN THE WHOLE AREA OF DISABILITY, AND WHAT THE PUBLIC'S EXPECTATIONS -- AND RESPONSIBILITIES -- MIGHT REASONABLY BE.

IN THE 1930's IT REALLY WAS ONE MAN -- A FEDERAL OFFICIAL -- THE PRESIDENT OF THE UNITED STATES, F.D.R. -- WHO SUCCEEDED IN CAPTURING PUBLIC ATTENTION AND FOCUSING IT UPON PARALYTIC POLIO. BUT THAT'S AS FAR AS THE GOVERNMENT WENT. IT WAS AN ERA BEFORE THE ESTABLISHMENT OF THE NATIONAL INSTITUTES OF HEALTH, BEFORE GOVERNMENT DEVELOPED THE MECHANISMS IT HAS TODAY TO SUPPORT INDIVIDUAL RESEARCHERS HERE AND AROUND THE WORLD.

AND, AS TERRIBLE A QUESTION AS IT MAY SEEM, WE HAVE TO STOP AND ASK OURSELVES WHAT WOULD HAVE BEEN THE HISTORY OF THE FIGHT AGAINST POLIO IF PRESIDENT ROOSEVELT HAD BEEN ABLE-BODIED AND NOT DEPENDENT ON A WHEELCHAIR AND CRUTCHES. I SAY IT IS A TERRIBLE QUESTION, SINCE IT POSES FOR US THE CONSTANT SENSE OF UNEASINESS WE HAVE ABOUT THE BASIC INSTINCTS OF MANKIND.

JOSEPH WOOD KRUTCH, THE NATURALIST AND CRITIC, A MARVELOUS WRITER, DESCRIBED PEOPLE....AS HE SAW THEM....IN HIS BOOK CALLED <u>HUMAN NATURE AND THE HUMAN CONDITION</u>. KRUTCH WROTE,

"WHAT SOME OF US TEND TO CALL 'THE HUMAN BEING' FIRST CAME INTO RECOGNIZABLE EXISTENCE ABOUT THE YEAR 475 B.C. AND BEGAN TO DISAPPEAR ABOUT SEVENTY-FIVE YEARS AGO."

THAT IS A WRY VIEW OF OURSELVES, BUT IT SAYS IN A HUMOROUS WAY WHAT MANY OF US TAKE VERY SERIOUSLY: THE QUESTION OF WHETHER -- AND HOW -- YOU CAN CONVINCE PEOPLE TO FOLLOW THEIR OWN HIGHEST INSTINCTS WITHOUT AN AWFUL LOT OF EFFORT.

FRANKLIN ROOSEVELT HAD THAT KIND OF GIFT. AND THE BENEFICIARIES, MANY OF THEM, ARE HERE TODAY. HIS EXAMPLE IS PARTICULARLY APPROPRIATE, BECAUSE IT DOES DEMONSTRATE THAT GOVERNMENT MAY NOT NECESSARILY BE THE KEY TO THE SOLUTIONS OF OUR PROBLEMS. ONE PERSON WITH A SENSE OF PURPOSE -- AND MASSES OF PEOPLE FOLLOWING THEIR OWN BEST INSTINCTS AS PRIVATE INDIVIDUALS -- MAY BE FAR MORE IMPORTANT.

THE MARCH OF DIMES, THE NATIONAL EASTER SEAL SOCIETY, WHO ARE AMONG THE CO-SPONSORS HERE, AND MANY OTHER PRIVATE VOLUNTARY ORGANIZATIONS PROVIDE AN OUTLET FOR ACTION THAT CANNOT BE UNDER-ESTIMATED. ABOUT A MONTH AGO, PRESIDENT REAGAN MET WITH A NUMBER

OF REPRESENTATIVES OF PRIVATE VOLUNTEER GROUPS. HE SAID, "I HAVE A DISTINCT FEELING, AND HAVE FOR A LONG TIME, THAT WE HAVE DRIFTED, AS A PEOPLE, TOO FAR AWAY FROM THE VOLUNTARISM THAT SO CHARACTERIZED OUR COUNTRY FOR SO MANY YEARS." HE ASKED THE REPRESENTATIVES -- AND THROUGH THEM HE ASKED THE NATION -- TO REDISCOVER THAT VAST HUMAN STRENGTH THAT HAS BEEN A PART OF OUR SOCIAL FABRIC SINCE THIS NATION WAS FOUNDED.

I WOULD SUGGEST THAT THE SIGNIFICANCE OF THE VOLUNTARY EFFORT THROUGHOUT THE POLIO EXPERIENCE NEEDS TO BE ADDRESSED. IT WAS SUBSTANTIAL, BUT EVEN AT THAT, IT MAY PROVE TO BE NOT A COMPLETELY ADEQUATE MODEL FOR TODAY'S REQUIREMENTS. WE HAVE COME TO A STAGE IN OUR HISTORY WHEN THE FEDERAL GOVERNMENT HAS BECOME OVER-BURDENED WITH A GREAT VARIETY OF SOCIAL AND HUMAN SERVICES. IT DOES THE OBVIOUS THING -- IT PASSES THE COSTS ON TO THE TAXPAYER. OR AT LEAST, THAT HAS BEEN THE APPROACH.

TODAY, WE ARE WRESTLING WITH THE ISSUE OF APPROPRIATE BALANCE AND WE ARE TAKING ALL THE STEPS NECESSARY TO REMOVE THE FEDERAL GOVERNMENT FROM MANY ACTIVITIES FOR WHICH IT MAY NO LONGER BE THE MOST APPROPRIATE OR COST-EFFECTIVE AGENT. WE'RE TAKING SOME

OF THOSE BURDENS AWAY. BUT NOW, INSTEAD OF PASSING THE COSTS BACK TO THE TAXPAYER, WE ARE PASSING THE TASKS THEMSELVES BACK TO THE PEOPLE BEST SUITED TO HANDLE THEM.

SOMETIMES THESE ARE STATE AND LOCAL GOVERNMENTS. BUT VERY OFTEN THEY ARE PRIVATE, VOLUNTARY ORGANIZATIONS. THAT IS THE STRONG FEELING OF THE PRESIDENT -- AND I BELIEVE HE IS RIGHT. THIS IS THE CONTEXT OF FEDERAL PLANNING AT THIS TIME, AS WE TURN TO THE CHALLENGES OF THIS DECADE.

AND WE CERTAINLY ARE NOT LACKING FOR CHALLENGES OF EVERY SORT. LET ME SHARE SOME OF THEM WITH YOU AND SUGGEST WHAT OUR RESPONSE MAY BE.

AS YOU ARE NO DOUBT AWARE, THIS COUNTRY HAS BEEN MAKING STEADY PROGRESS IN THE IMPROVEMENT OF HEALTH STATUS. FOR THE PAST 20 YEARS THERE HAS BEEN A STEADY DECLINE IN THE AGE-ADJUSTED MORTALITY RATES AMONG FOUR OF THE FIVE LEADING CAUSES OF DEATH:

HEART DISEASE, STROKE, ACCIDENTS, AND INFLUENZA AND PNEUMONIA. THE STORY IN CANCER, THE SECOND LEADING CAUSE OF DEATH IN THIS COUNTRY, IS MIXED. FOR PERSONS UNDER THE AGE OF 45, THE MORTALITY RATE HAS DROPPED ABOUT 33 PERCENT. WE HAVE ALSO HAD DRAMATIC SUCCESS WITH CERTAIN CANCERS THAT AFFECT YOUNG PEOPLE -- LEUKEMIA, HODGKIN'S DISEASE, AND TESTICULAR CANCER, FOR EXAMPLE. ON THE OTHER HAND, THERE HAVE BEEN INCREASES IN MORTALITY FOR CANCERS IN CERTAIN SITES, SUCH AS THE BREAST, COLON, PANCREAS, AND THE RESPIRATORY SYSTEM.

IN OTHER WAYS, TOO, WE HAVE AN IDEA THAT OUR NATIONAL APPROACH TO PREVENTING PREMATURE DEATH MAY BE SUCCEEDING, EVEN THOUGH THE RECORD MAY BE MIXED. FOR EXAMPLE, OUR LIFE EXPECTANCY HAS BEEN INCREASING; IT'S NOW ABOUT 73.6 YEARS FOR A CHILD BORN TODAY. BUT THAT'S AN AVERAGE; THERE'S A WIDE DISCREPANCY BETWEEN, FOR EXAMPLE, THE EXPECTANCY FOR A BLACK MALE IT'S ABOUT 65 YEARS AND FOR A WHITE FEMALE IT'S ABOUT 78 YEARS.

SIMILARLY, OUR INFANT MORTALITY RATES HAVE COME DOWN, AS SHOULD BE THE CASE FOR AN ADVANCED, INDUSTRIAL SOCIETY. WE ARE AT ABOUT 12.5 INFANT DEATHS PER 1,000 LIVE BIRTHS. HERE AGAIN, THERE ARE VARIATIONS, WITH BLACKS AT ABOUT TWICE THAT NATIONAL AVERAGE, CHINESE-AMERICANS AT ABBOUT HALF THE NATIONAL AVERAGE, AND WHITES A BIT ABOVE THE NATIONAL AVERAGE.

THAT IS AN IMPRESSIVE RECORD FOR THIS COUNTRY, A RECORD WE WOULD WANT TO IMPROVE IN THE YEARS AHEAD. I FEEL SURE WE WILL. THE REASONS I HAVE FOCUSED ON THESE DRAMATIC MORTALITY STATISTICS IS THAT THEY MAY BE MASKING A VERY CHALLENGING PICTURE OF MORBIDITY AND DISABILITY. IN A TYPICAL YEAR, THE CENTERS FOR DISEASE CONTROL WILL BE CALLED IN TO INVESTIGATE SOME 1,700 OUTBREAKS OF INFECTIOUS DISEASES. AS YOU KNOW, THERE ARE ONLY A HANDFUL OR LESS OF POLIO CASES A YEAR. BUT WE ARE EXPERIENCING A STEADY RISE IN THE NUMBER OF SEXUALLY TRANSMITTED DISEASES, SUCH AS GONORRHEA AND SYPHILIS, GENITAL HERPES AND CHLAMYDIA. OVER 2 MILLION CASES A YEAR COST THIS COUNTRY MORE THAN $L BILLION IN SURVEILLANCE, DIAGNOSIS, AND TREATMENT.

INFLUENZA AND PNEUMONIA STILL RANK AMONG THE 10 LEADING CAUSES OF DEATH AND ARE OUR MOST PERSISTENT INFECTIOUS DISEASES GENERALLY. EACH YEAR WE TRY TO PREPARE OURSELVES WITH THE RIGHT VACCINES IN THE RIGHT QUANTITIES FOR AN ANTICIPATED OUTBREAK OF INFLUENZA -- AND WE MAY GUESS RIGHT OR WRONG. THERE ARE MANY STRAINS WE KNOW ABOUT -- AND THERE ARE NO DOUBT MANY MORE STRAINS WE ARE GOING TO KNOW ABOUT AND MAY NOT BE ADEQUATELY PREPARED TO FIGHT. WE HAVE A SOMEWHAT SIMILAR SITUATION WITH PENICILLIN-RESISTANT STRAINS OF GONOCOCCAL BACTERIA THAT ARE BEGINNING TO APPEAR.

IN ADDITION, WHAT HAS BECOME AN ESPECIALLY WORRISOME PROBLEM IS THE RISE IN THE INCIDENCE OF NOSOCOMIAL DISEASES, THE INFECTIONS PICKED UP IN HOSPITALS AND OTHER TREATMENT FACILITIES. THESE ALSO TEND TO BE DRUG-RESISTANT, SINCE THEY'VE BEEN GROWING IN THE WARM AND COZY TREATMENT ENVIRONMENT.

HENCE, PARALLEL WITH OUR VICTORIES IN PREVENTING PREMATURE DEATH IS A MURKY PICTURE OF SUCCESS AND FAILURE REGARDING MORBIDITY.

TO GET SOME PERSPECTIVE ON THE SLOW BUT STEADY RISE IN THE NUMBER OF AMERICANS WHO ARE DISABLED EACH YEAR, WE CAN LOOK BACK TO 1969, WHEN 11.6 PERCENT OF THE POPULATION WERE DISABLED. THAT IS, NEARLY 23 MILLION PEOPLE WERE LIMITED IN SOME WAY FROM CARRYING OUT NORMAL ACTIVITIES OF THEIR AGE GROUP AND SEX. BY 1973, THE TOTAL HAD RISEN TO 13.3 PERCENT OF THE POPULATION, OR 28 MILLION. IN 1978, THE TREND CONTINUED, WITH 13.6 PERCENT OF THE POPULATION LIMITED OR DISABLED IN SOME WAY -- OR SLIGHTLY MORE THAN 30 MILLION PEOPLE. THE TREND SEEMS TO BE CONTINUING STILL, AND WE CAN ASSUME THAT ABOUT 1 IN 7 AMERICANS IS DISABLED, LIMITED IN SOME WAY FROM LIVING A LIFE THAT IS NORMAL FOR HIS OR HER AGE GROUP.

WHAT WE HAVE, THEN, IS A POPULATION IN WHICH AN EVER-INCREASING PERCENTAGE IS CONSIDERED TO BE EITHER TEMPORARILY OR PERMANENTLY DISABLED. WHILE THEY MAY NO LONGER APPEAR AMONG THE MORTALITY STATISTICS, THEY MAY BE AMONG THE MORBIDITY AND DISABILITY STATISTICS, PERSONS WHO HAVE NOT DIED OF HEART DISEASE, BUT WHO ARE AMONG 5 MILLION OR SO WHO ARE LIMITED IN WHAT THEY CAN DO FOR THE REST OF THEIR LIVES....

....PERSONS WHO WERE NOT VICTIMS OF PARALYTIC POLIO, BUT WHO ARE NEVERTHELESS AMONG THE NEARLY 5 MILLION WHO SUFFER FROM IMPAIRMENTS OF THE BACK, SPINE, SHOULDERS, AND UPPER AND LOWER EXTREMITIES...

....PERSONS WHO HAVE NOT DIED OF RESPIRATORY CANCER, BUT WHO ARE AMONG THE 3 TO 4 MILLION WHO LIVE WITH DISABLING AND CHRONIC BRONCHITIS, ASTHMA, EMPHYSEMA, AND OTHER RESPIRATORY CONDITIONS...

....AND PERSONS WHO HAVE MANAGED TO TAKE ADVANTAGE OF GAINING ADDITIONAL YEARS OF LIFE, BUT WHO DO SO AMONG THE 6 MILLION OR MORE WHO SUFFER FROM ARTHRITIS, RHEUMATISM, AND OTHER MUSCULO-SKELETAL DISORDERS.

TO DATE, WE HAVE A MIXED HISTORY REFLECTING OUR ABILITY -- AS A WEALTHY AND COMPASSIONATE NATION -- TO DEAL WITH THIS RANGE OF DISABLING CONDITIONS AMONG SO MANY MILLIONS OF PEOPLE. IN ADDITION, WE ARE ONLY NOW BEGINNING TO MEASURE -- IN HARD DOLLARS -- THE COST OF THESE DISABLING CONDITIONS UPON THE SOCIETY AS A WHOLE.

FROM THE DATA COLLECTED IN THE NATIONAL HEALTH INTERVIEW SURVEY, WE'VE BEEN ABLE TO ESTIMATE THE ECONOMIC BURDEN OF DISABILITY FOR 1977, THE LATEST YEAR FOR WHICH WE HAVE THE FIGURES. A TOTAL OF 496 MILLION DAYS WERE REPORTED AS LOST FROM WORK BECAUSE OF ACUTE OR CHRONIC CONDITIONS. THE TOTAL EARNINGS LOST BY PERSONS MISSING FROM WORK FOR THOSE CONDITIONS AMOUNTED TO $25.6 BILLION. FOR THOSE PERSONS, SOMEBODY OR SOME AGENCY HAS TO MAKE UP THE LOST INCOME. IT MAY BE WORKER'S COMPENSATION OR INSURANCE, IT MAY BE A RELATIVE OR A FRIEND, IT MAY BE A CHARITABLE ORGANIZATION, OR IT MAY SIMPLY BE LOST. EXCEPT FOR THE LAST OUTCOME, WE HAVE TO ASSUME THAT THERE IS A TRANSFER OF THAT MONEY FROM ONE KIND OF ACTIVITY ACCOUNT INTO THE OTHER -- THE PAYMENT OF FOREGONE INCOME.

IT WOULD BE A RATHER SIMPLE BOOKKEEPING MATTER -- IF IT DID NOT INVOLVE $25.6 BILLION. SO THAT IS ONE KIND OF ECONOMIC BURDEN.

A DIFFERENT KIND OF BURDEN IS THAT OF LOST PRODUCTIVITY. WHAT IS THE POTENTIAL VALUE OF THE GOODS AND SERVICES THAT MIGHT HAVE BEEN PUT INTO THE MARKETPLACE, IF ALL PERSONS OVER THE AGE OF 16 WERE ABLE TO WORK? THAT IS, THEY SUFFERED FROM NO ILLNESS OR DISABILITY. WE ARE NOT COMPUTING THE LOSS OF HEALTHY, ABLE-BODIED PERSONS WHO ARE UNEMPLOYED.

IN 1977, ACCORDING TO THE LABOR DEPARTMENT, THERE WERE 2.8 MILLION PERSONS WHO COULD NOT WORK BECAUSE OF ILLNESS OR DISABILITY. THESE PEOPLE ARE DIFFERENT FROM THOSE WHO LOST DAYS FROM WORK -- THE ONES WHO MISSED $25.6 BILLION IN INCOME. NOW WE ARE TALKING ABOUT PEOPLE WHO ARE NOT IN THE WORK-FORCE AT ALL, 2.8 MILLION OF THEM. IT IS ESTIMATED THAT THE LOSS OF THEIR PRODUCTIVITY IN 1977 COST OUR COUNTRY $23 BILLION.

IN ADDITION, ECONOMISTS HAVE PLACED VALUE ESTIMATES ON KEEPING HOUSE; THAT IS, THE VALUE OF HOUSEKEEPING, IF YOU HAD TO GO OUT AND HIRE SOMEONE TO DO IT. IT RANGED FROM $9,718 A YEAR FOR A WOMAN IN HER LATE 20s TO $5,503 FOR A WOMAN ABOVE THE AGE OF 65. THAT'S IN 1977 DOLLARS. DURING THAT YEAR, THERE WERE 1.3 MILLION WORK-YEARS LOST AS A RESULT OF DISABLING CONDITIONS AMONG HOUSEKEEPERS -- FOR A TOTAL SOCIAL COST OF $6.3 BILLION.

IF YOU ADD UP THESE THREE FIGURES -- THE LOSSES AMONG PERSONS WHO ARE EMPLOYED BUT MISS WORK-DAYS, THE LOSSES FROM PERSONS WHO ARE NOT EMPLOYABLE BECAUSE OF CHRONIC ILLNESS OR DISABILITY, AND THE LOSSES AMONG ILL OR DISABLED HOMEMAKERS -- WE ARRIVE AT THE ESTIMATE FOR THE 1977 ECONOMIC BURDEN OF ILLNESS IN THIS COUNTRY : $54.9 BILLION, A SIZEABLE OUTPUT LOSS FOR OUR SOCIETY.

THE MAJOR CAUSE OF THESE LOSSES IS HEART DISEASE. ACCIDENTS ARE THE SECOND MAJOR CAUSE; ALL CANCERS, OR NEOPLASMS, ARE THE THIRD: AND STROKE IS THE FOURTH.

THESE KINDS OF ESTIMATES HAVE BEEN DEVELOPED FOR THE PAST SEVERAL YEARS BY A NUMBER OF ECONOMISTS AND STATISTICIANS. THE FIGURES I AM RELYING ON ARE DRAWN FROM WORK DONE BY MRS. DOROTHY RICE, DIRECTOR OF THE NATIONAL CENTER FOR HEALTH STATISTICS, AND ONE OF THE PIONEERS IN THIS NEW AREA OF HEALTH ECONOMICS.

THIS KIND OF INFORMATION IS ESPECIALLY USEFUL IN TIMES OF FISCAL AND BUDGETARY AUSTERITY. WE ARE IN ONE OF THOSE PERIODS NOW. SO WE HAVE TO MATCH THOSE KINDS OF DATA WITH THE KNOWLEDGE AND EXPERIENCE OF THE DISABLED PERSON -- IN OTHER WORDS, WITH INFORMATION FROM MEETINGS SUCH AS THIS. AND FROM THAT MIX, ALONG WITH OTHER INGREDIENTS, WE SHOULD BEGIN TO SEE THE OUTLINES OF A NEW AND MORE EFFECTIVE NATIONAL POLICY FOR MEETING THE CHALLENGE OF CHRONIC ILLNESS AND DISABILITY IN THE AMERICA OF THE 1980s AND 90s.

FOR EXAMPLE, I THINK ALL OF US CAN AGREE ON -- OR AT LEAST AGREE TO TAKE SERIOUSLY -- SEVERAL PROPOSITIONS:

FIRST, IT IS UNWISE TO APPROACH THIS PROBLEM ON A DISEASE-BY-DISEASE OR DISABILITY-BY-DISABILITY BASIS. AS THE STATISTICS INDICATE, MANY PERSONS SUFFER FROM MULTIPLE DISEASE OR DISABILITY CONDITIONS. ALSO, EACH OF US WOULD HAVE TO SAY THAT EVERY CONDITION REQUIRED 100 PERCENT OF OUR MONEY AND EFFORT, IF WE FOLLOWED THAT APPROACH. THERE ARE RELATIONSHIPS THAT HAVE TO BE WEIGHED, INCLUDING THE RELATIONSHIP OF THE CONDITION TO ITS TOTAL EFFECT ON SOCIETY AND THE ECONOMY.

I MIGHT ADD THAT THE NATIONAL INSTITUTES OF HEALTH HAVE EMBARKED ON THIS KIND OF RESEARCH PLANNING, ALSO. THEY ARE LOOKING AT SOME PROBLEMS, SUCH AS NUTRITION, AS MATTERS TO BE STUDIED BY SEVERAL OR EVEN ALL THE INSTITUTES. IT IS A SERIOUS AND HIGHLY VALUABLE EFFORT TO BREAK DOWN THE BARRIERS BETWEEN INSTITUTES -- WHICH IS AN ORGANIZATIONAL PROBLEM -- AND BARRIERS BETWEEN RESEARCHERS IN DIFFERENT DISEASE OR DISABLING CONDITIONS -- WHICH IS A CONCEPTUAL PROBLEM.

SECOND, WE MUST ASCERTAIN AS BEST WE CAN WHO PAYS WHAT COSTS FOR CHRONIC ILLNESS AND DISABILITY AND IF THAT IS A FAIR EXPRESSION OF HOW WE AS A SOCIETY WANT THE BURDEN TO BE SHARED. IN MANY CASES, WE SEEM CONTENT TO LET THE BURDEN FALL MOST HEAVILY UPON THOSE PERSONS AND THEIR FAMILIES WHO ARE DIRECTLY AFFECTED BY THE DISABILITY. RELATIVE TO THE SIGNIFICANCE OF THEIR EXPERIENCE TO THE TOTAL HEALTH AND WELL-BEING OF SOCIETY, THAT WOULD NOW SEEM TO BE AN OBSOLETE ANSWER. ON THE OTHER HAND, NOT ALL PERSONS IN SOCIETY CAN CONTRIBUTE A SHARE OF HELP. NOT ALL PAY TAXES, NOT EVERYONE CAN MAKE CHARITABLE DONATIONS, NOT EVERYONE CAN CONTRIBUTE IN KIND, IF NOT DOLLARS.

IN OUR KIND OF SOCIETY, WHERE PARTICIPATION IN SOCIAL AND POLITICAL PROCESSES HAS A VERY HIGH VALUE, THIS IS AN IMPORTANT

ISSUE. IT IS, OF COURSE, THE CLASSIC DEBATE OF RIGHTS VERSUS RESPONSIBILITIES. I HAVE A RIGHT TO BE LEFT ALONE; TO DETERMINE HOW I WANT TO LIVE, AS LONG AS I DON'T INJURE ANYONE IN THE PROCESS. BUT I ALSO HAVE THE RESPONSIBILITY TO SOMEHOW HELP OTHERS WHO WOULD LIKE TO EXERCISE THE SAME RIGHT -- BUT DON'T HAVE THE WHEREWITHAL TO DO SO.

AGAIN, IF I MAY INVOKE THE CURRENT ECONOMIC CONDITION, WE NEED TO ASSURE OURSELVES THAT OUR POLICIES DO NOT HAVE A DISPROPORTIONATE IMPACT UPON THE DISABLED AND THEIR FAMILIES. SO FAR, GOVERNMENT HAS MADE AN ATTEMPT TO BE FAIR AND MANY PRIVATE ORGANIZATIONS AND PROFESSIONS HAVE WORKED TO KEEP GOVERNMENT HONEST IN THAT REGARD. BUT THE GUARANTEE OF FAIRNESS IS EVERYONE'S TASK -- PUBLIC AND PRIVATE.

THIRD, WE'VE COME A LONG WAY IN OUR UNDERSTANDING OF THE ROLE TO BE PLAYED BY INSTITUTIONS OF CARE. IT'S A MUCH SMALLER ROLE THAN HAD ONE TIME BEEN IMAGINED. THE SWING AWAY FROM INSTITUTIONALIZATION IS GAINING INTEREST AND MOMENTUM AND MAKES A LOT OF SENSE FOR A LOT OF PEOPLE. BUT I WOULD HOPE THAT WE WOULD BEGIN TO GIVE DEEPER THOUGHT TO WHAT THE ALTERNATIVES ARE TO INSTITUTIONALIZATION.

ITEM: IT IS NOT ENOUGH TO WORK TOWARD MOVING RESPIRATOR-DEPENDENT INFANTS FROM OUR INTENSIVE CARE PEDIATRIC FACILITIES. WE NEED TO DO MORE WORK WITH PARENTS AND NEIGHBORHOOD GROUPS AND PUBLIC SERVICES TO MAKE SURE THE ALTERNATIVE FOR THE INFANT IS NOT AN ENVIRONMENT OF DANGER, LIFE-THREATENING OR UNCARING.

ITEM: A PROBLEM BEGINNING TO OCCUR AMONG THE ELDERLY IS THIS SAME ISSUE OF ALTERNATIVES. WE ARE AWARE THAT SOME WOMEN HOMEMAKERS, IN THEIR LATE 60s AND 70s, ARE GIVEN IN-PATIENT CARE FOR A PERIOD OF TIME BUT ARE THEN SENT BACK TO THE COMMUNITY, TO THEIR HOMES -- WHERE THERE MAY BE NO ONE TO CARE FOR THEM. THIS IS THE PHENOMENON OF THE AGED PARENT WHO HAS OUTLIVED HIS OR HER CHILDREN, WHO HAS SURVIVED STROKE OR HEART DISEASE THROUGH THE MIRACLE OF MEDICINE BUT WILL NOT SURVIVE THE ORDINARY STRESSES OF LIVING AT HOME WITHOUT ADDITIONAL CARE.

ITEM: AS I ILLUSTRATED WITH THE SLOWLY RISING TREND-LINE OF THE NUMBER OF DISABLED PERSONS IN OUR SOCIETY, THERE ARE MORE AND MORE PEOPLE WHO HAVE KNOWN INDEPENDENT LIVING AND WHO HAVE EXPERIENCED A PARTICULAR QUALITY OF LIFE PLEASING TO THEM, FOR WHOM BOTH INDEPENDENCE AND QUALITY MAY HAVE BEEN ERASED BY AN ILLNESS OR DISABILITY. OR SO IT MIGHT SEEM. BUT I CAN'T ACCEPT THAT AS A "GIVEN" PROPOSITION.

IN THIS INSTANCE I THINK SOCIETY HAS TO REDEDICATE ITSELF TO THE RIGHTS OF THE HANDICAPPED. AND I SAY "SOCIETY," NOT JUST GOVERNMENT OR ANY PARTICULAR SEGMENT OR SECTOR OF SOCIETY. WE CANNOT REPLACE LOST LIMBS OR DAMAGED ORGANS, WE MAY NOT BE ABLE TO REVERSE MENTAL RETARDATION OR CORRECT ALL BIRTH DEFECTS, BUT WE CAN TRY TO MAKE SURE THAT EVERY PERSON WITH THESE OR OTHER CONDITIONS IS ENCOURAGED TO TAKE PART TO THE FULLEST EXTENT IN OUR NATION'S WAY OF LIFE. AND WITH ENCOURAGEMENT GOES SOCIETY'S RESPONSIBILITY TO PROTECT THOSE INDIVIDUALS AS THEY PURSUE THEIR LEGITIMATE PERSONAL AND FAMILY GOALS.

I THINK THAT HAS TO BE PART OF THE DE-INSTITUTIONALIZATION MOVEMENT. WHAT GOOD IS IT, REALLY, IF WE REDUCE THE CHANCES OF A PERSON'S BEING UNFAIRLY INSTITUTIONALIZED -- ONLY TO DISCOVER THAT THE WALLS ARE JUST AS HIGH OUT IN THE COMMUNITY? WE'VE GOT OUR WORK CUT OUT FOR US ON THIS ONE.

FINALLY, THE DISABLED COMMUNITY -- PERSONS SUFFERING FROM CHRONIC DISEASE CONDITIONS AS WELL AS FROM PHYSICAL DISABILITIES -- THIS VERY VARIED COMMUNITY HAS HAD A RATHER HIGH LEVEL OF PARTICIPATION IN POLICY DEVELOPMENT AND PROGRAM IMPLEMENTATION OVER THE YEARS. SOMETIMES THE DISABLED THEMSELVES ARE INVOLVED, WHICH HAS BEEN THE CASE WITH POLIO VICTIMS, FOR EXAMPLE, OR THEY

VIGOROUSLY REPRESENTED BY SURROGATES AND ADVOCATES. BUT WE ARE JUST BEGINNING TO UNDERSTAND THE IMPORTANCE OF THIS KIND OF PARTICIPATION. AS THE MEDIAN AGE OF AMERICANS CONTINUES TO RISE, THE MEDIAN AGE OF DISABLED PERSONS IS RISING, TOO. WE CAN EXPECT, THEREFORE, TO HEAR FROM A NEW AND MORE COMPLEX CONSTITUENCY IN THE FUTURE -- OLDER PERSONS WHO ARE DISABLED OR SUFFER FROM A CHRONIC CONDITION, YET DEMAND, AS IS THEIR RIGHT, TO PARTICIPATE FULLY IN THE DECISIONS OF THEIR POLITY AND OF SOCIETY IN GENERAL.

I THINK SOCIETY ITSELF, AS WELL AS EACH ORGANIZATION THAT REPRESENTS THE DISABLED, NEEDS TO ASK ITSELF WHETHER OR NOT IT IS EQUIPPED TO GROW WITH THESE CHANGES AND TO ACCEPT AND CARRY OUT THE RESPONSIBILITIES OF THE FUTURE. IT IS ONE THING TO EXTOLL THE VIRTUES OF OUR PARTICIPATORY DEMOCRACY; IT IS ANOTHER THING TO CARRY THEM OUT. WE OUGHT TO DO BOTH THOSE THINGS JUST AS WELL AS WE CAN -- NOW AND FOR THE DECADES TO COME.

AS YOU CAN TELL, I DID NOT COME HERE THIS AFTERNOON WITH A BRIEFCASE FULL OF ANSWERS. NOR DID I COME WITH THE PARTICULAR FOCUS OF THE POLIO EXPERIENCE. THAT IS AN INVALUABLE EXPERIENCE AND IT WILL CONTRIBUTE TO HOW WE WORK IN THE FUTURE ON BEHALF OF

ALL OUR CITIZENS WITH WHATEVER CHRONIC ILLNESSES AND DISABILITIES. BUT I DID COME HERE TODAY TO SHARE WITH YOU SEVERAL OF THE QUESTIONS THAT WE ALL NEED TO STUDY AND ANSWER:

* HOW DO WE MAINTAIN OUR MORAL AND ETHICAL COMMITMENTS WITH A RE-DRAWN AND CONSTRAINED FEDERAL PRESENCE?

* HOW DO WE GUARANTEE EQUITY AND COMPASSION IN THE MIDST OF A GROWING COMPLEXITY OF INFORMATION AND ISSUES?

* HOW DO WE CHANGE THE TRADITIONAL BEHAVIOR OF INDIVIDUALS AND INSTITUTIONS TOWARD THE DISABLED, IN LIGHT OF THE GROWING COMMUNITY OF SUCH PERSONS?

* AND HOW DO WE BRING BACK INTO THE BALANCE THE SHARING OF RESPONSIBILITIES AND COSTS AMONG BOTH THE PUBLIC AND THE PRIVATE SECTORS, THE INDIVIDUAL AND THE COMMUNITY?

I KNOW YOU WILL, AS INDIVIDUALS AND COLLECTIVELY, BE SEEKING ANSWERS TO THESE QUESTIONS IN THE DAYS TO COME. I WANT YOU TO KNOW THAT THOSE ANSWERS HAVE A HIGH PRIORITY FOR ME PERSONALLY IN MY ROLE IN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES.

IN CLOSING, PLEASE LET ME EXTEND ONCE AGAIN MY CONGRATULATIONS TO THE PLANNERS OF THIS MEETING. THANK YOU AGAIN FOR HAVING ME JOIN YOU. I CERTAINLY DO LOOK FORWARD TO A SUMMARY OF WHAT HAS TAKEN PLACE HERE.

THANK YOU.

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